# Using Community-Based Participatory Research to Assess the Needs of HIV-Related Services for Infected Individuals in Rural Communities

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**Abstract**

HIV/AIDS remains a significant health concern in rural communities, which may also experience many disparate issues including reduced access to health services (Department of Health and Human Services, 2015). Community efforts should be increased to improve services to people living with HIV/AIDS (PLWHA), especially in rural communities. In the state of Tennessee, using a community-based participatory research (CBPR) approach, a needs assessment was conducted to identify gaps, barriers, and strategies for improving HIV-related comprehensive care services for people diagnosed with HIV/AIDS in 26 rural counties. The paper describes the CBPR partnership and the needs assessment project that was conducted and how the results may support community leaders and health care providers in planning and allocating resources for non-medical services of PLWHA in rural communities, and thus maximizing both individual and community benefit.

Of the estimated 1.1 million Americans age 13 and older living with the human immunodeficiency virus (HIV), approximately 50,000 were living in rural areas at the end of 2009 (Health Resources and Services Administration, n.d.-a). A study conducted by Cohn, Berk, Berry, Duan, Frankel, Klein, McKinney, Rastegar, Smith, Shapiro, and Bozette (2001) concluded that few adults with HIV in rural areas of the United States received HIV care. Rural residents with HIV have health care needs similar to those of their urban counterparts including general health care (Iyer, 2015). Access to quality health care for people living with HIV/AIDS in rural areas is harder to come by than one would think. Rural residents face the absence of qualified health care personnel (i.e., primary, dental, and mental health care providers) along with barriers to federal assistance for HIV care (Iyer, 2015). In rural America, the Ryan White HIV/AIDS Federal Program is a critical source of support, helping PLWHA overcome barriers to care such as health insurance and financial resources (Health Resources and Services Administration, n.d.-b; Iyer, 2015). The highest uninsured rates in 2016 were among people who live in the South or West regions of the United States, and most of the people living in these two regions have been without insurance coverage for long periods of time (Kaiser Family Foundation, 2017). In Tennessee, the HIV/AIDS/STD Section of the Tennessee Department of Health (TDOH) received federal funds from the Ryan White HIV/AIDS (Part B) Federal Program to cover HIV non-medical services and cost-efficient systems for the delivery of services to individuals with HIV disease and their caregivers and families in 26 rural counties in Middle Tennessee. In 2015, the Community HIV/AIDS Partnership (CHAP) worked in conjunction with the United Way of Metropolitan Nashville (UWMN) and faculty researchers from Tennessee State University to assess the needs of HIV/AIDS prevention services and care in these counties to make recommendations to TDOH for allocation of Ryan White HIV/AIDS (Part B) funds based on prioritized needs. A summary description of organizations and HIV-related terms discussed in this article are shown in Table 1.

**Purpose**

This study has two purposes. First, it describes the collaboration of faculty researchers from Tennessee State University and community partners (CHAP members and UWMN staff) to conduct a needs assessment project regarding HIV-related services for PLWHA in the study area. A CBPR approach was used as a guide to conduct the needs assessment project among faculty researchers and community partners. As noted by Wallerstein and Duran (2006), CBPR is an alternative research paradigm that involves all partners in the research process and integrates

**Table 1.** Organizations and HIV-Related Terms

| Organizations | Definitions |
|---|---|
| Community HIV/AIDS Partnership (CHAP) | The Community HIV/AIDS Partnership is a consortium of community leaders, community-based organizations, healthcare providers, local public health agencies, and individuals infected and affected by HIV/AIDS. |
| Tennessee Department of Health (TDOH) | The Tennessee Department of Health is an agency of the Tennessee state government responsible for public health. |
| United Way of Metropolitan Nashville (UWMN) | This community agency works to improve the lives of people in Nashville by focusing on health, education and financial stability. |
| **HIV-Related Terms** | **Definitions** |
| Human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) | This term is used to describe the infections caused by the Human Immunodeficiency Virus that can lead to HIV/AIDS. |
| Immune Assistance Plan (IAP) | This program assists eligible HIV-positive individuals with health insurance premiums, co-pays, and deductibles. |
| Intravenous drug users (IDU) | This term refers to individuals who inject a substance into their veins using a syringe. |
| Men who have sex with men (MSM) | This term refers to male persons who engage in sexual intercourse with members of the same gender. |
| People living with HIV/AIDS (PLWHA) | People living with HIV/AIDS have been diagnosed with the human immunodeficiency virus/acquired immune deficiency syndrome. |

education and social action to improve health and reduce health disparities. For this reason, the CBPR approach was chosen to guide the needs assessment project. Second, this study presents the results obtained through the needs assessment project conducted by faculty researchers and community partners.

## Methods

*Design and Sample*

Consistent with the CBPR approach, faculty researchers and graduate students from Tennessee State University worked collaboratively with community partners to design the needs assessment activities, develop the data collection instruments, and interpret the results of the study. The research study employed a mixed methodology of quantitative and qualitative approaches to collect data from the participants. The key activities of the needs assessment included conducting an epidemiological data assessment, completing revisions on a resource audit, administering two surveys, and facilitating three focus group sessions. The population from which the sample was drawn entailed service recipients (i.e., PLWHA), family members of PLWHA, and service providers within the 26 Middle Tennessee catchment area. The faculty researchers obtained approval from the Institutional Review Board at Tennessee State University to conduct the study.

*Data Collection*

The faculty researchers and community partners agreed to use both qualitative and quantitative methods to conduct the needs assessment project. The first data collection activity entailed conducting an epidemiological assessment of PLWHA in the 26-county rural area to better understand specific populations as it relates to: 1) the most heavily burdened by the HIV epidemic, 2) experiences of infected individuals, 3) opinions related to the HIV care continuum from initial linkage, 4) subsequent retention in HIV care and services, and 5) long-term adherence to HIV treatment. Current gaps in services, consumer needs, and challenges that impact treatment attrition were also evaluated. Numerous state and local officials were contacted by faculty researchers and graduate students via telephone, email, and face-to-face communication to gather the epidemiological data. Additional data were compiled from the TDOH (i.e., HIV/AIDS/STD

section) using data reported in the Tennessee Electronic HIV/AIDS Reporting System for the years 2010–2014.

Second, a resource audit within the 26-county area was also conducted to assess the services currently available for PLWHA. The services commonly available to PLWHA were gathered through a comprehensive web search and information provided by PLWHA. The data were subsequently entered into an electronic database for assessment.

Third, two surveys (i.e., one for PLWHA and one for service providers) were developed and administered to PLWHA to evaluate their experiences regarding HIV non-medical services, challenges, and facilitators who impact their utilization of services, and their met and unmet service needs. CHAP members and the UWMN Community Impact Unit, under the consultation of the faculty researchers, compiled a 31-question quantitative survey and a 12-item qualitative survey (Brown, Johnson, Inman, Brown, Briggs, Burrell, Theriot, Williams, Buford, Burton, & Burton, 2015). PLWHA, who received services through the primary health care agencies in the 26-county area, were invited to complete the survey. If individuals were interested in completing the survey, the UWMN staff distributed the survey via mail. Individuals were informed via mail that the survey was voluntary and confidential. Survey respondents mailed back their completed surveys to UWMN staff. To prepare for data entry and analysis, the completed surveys were sent from UWMN to the faculty researchers. The second survey, the service provider survey, was generated to collect information about perceptions of service providers regarding the gaps in comprehensive care of individuals diagnosed with HIV/AIDS and their families. The questions for the service provider survey were developed based on findings presented in previous years' needs assessment reports and comments shared during a planning meeting with faculty researchers and community partners. To increase completion rates, the length of the service provider survey was kept short (six questions) to reduce the time it takes the providers to complete the survey. The provider survey was loaded into Survey Monkey, and a survey link was created. The link to the survey was sent to the identified providers servicing the 26-county area. After collecting all of the data from the service provider survey, the results were entered into a Microsoft Excel spreadsheet by graduate students.

The fourth and final data collection activity involved conducting focus groups within the 26-county area. The purpose of the focus groups was to assess whether gaps existed in services and resources among PLWHA in the area. The faculty researchers, in collaboration with the community partners, prepared the focus group survey items, scheduled the focus group sessions, and provided the incentive gift cards for participants.

All volunteering participants received a gift card at the conclusion of the focus group session. The gift card incentive was provided to enhance the community engagement and provided an opportunity to promote access to health care. The gift card could be used for food, gas, or hygiene products.

The focus group sessions were conducted across three separate regions in the 26-county area over a three-day period in two-hour sessions each day). All focus group participants—PLWHA and their families/caregivers—were part of a convenience sample. Informed consent was obtained from all participants. Confidentiality and full-disclosure statements were read to the participants. A 12-item focus group questionnaire was used to gather information and feedback. All data collected were anonymous and demographic quantitative data were collected before the focus group session began. Each focus group session followed the same format. The faculty researchers documented the responses from each focus group session through the use of note-taking and audio recordings. Two note takers and two audio recording devices were used to capture the qualitative data.

*Data Analysis*

The analysis of the quantitative survey data involved using SPSS Statistics 20.0. Frequencies and percentages were calculated to determine demographic characteristics of participants, criminal justice status, educational level, living conditions, and service utilization. The qualitative data collected from each of the focus group sessions were transcribed and analyzed using the qualitative software Atlas.ti7. During the qualitative data analysis process, common themes were identified that emerged from the participant discussions.

To improve the accuracy and credibility of the study findings, a member checking technique (Lee, Hoffman, & Harris, 2016) also known as "informant feedback" or "response validation" was employed by the faculty researchers to gather feedback from PLWHA about the preliminary findings of the needs assessment project. Also, consistent with the CBPR approach, the faculty researchers debriefed

the community partners about updates regarding the needs assessment project and preliminary findings on a regular basis. Lincoln and Guba's study noted (as cited in Creswell & Miller, 2000) that peer reviews or debriefings provide support, play devil's advocate, challenge the researchers' assumptions, push the researchers to the next step methodologically, and ask hard questions about methods and interpretations. Over a two-month period, debriefings and member checking were carried out at several meetings held among faculty researchers, community partners, and PLWHA. A PowerPoint presentation and handouts, with content from the quantitative and qualitative results, were also shared during the meetings by faculty researchers to help the community partners and PLWHA understand the initial findings. Consequently, the faculty researchers sought to integrate the feedback from the community partners and PLWHA into the final results of the study findings.

## Results

This section presents the results of the needs assessment project. The results are organized by the data collection methods, which include an epidemiological data assessment, resource audit, surveys, and focus groups.

### *Epidemiological Data Assessment*

At the end of 2014, there were 997 PLWHA residing in the 26-county area and 4,975 PLWHA living in the metropolitan regions of Middle Tennessee. In this study, the term HIV prevalence is used to describe how many people are living with HIV disease at a given time, regardless of when HIV infection was diagnosed. Among the 26-county area, the prevalence of HIV disease has continued to rise over the past five years (i.e., 2010–2014), increasing from 829 to 997. HIV disease incidence refers to people who were newly diagnosed with HIV disease. From 2010 to 2014, the proportion of new HIV diagnoses in the 26-county area was approximately three times higher for men, comprising 77.7% of the total reported (i.e., 264 cases) and non-Hispanic whites (61.4%).

### *Resource Audit*

The most commonly needed services identified by PLWHA in the 26-county area were basic dental providers, disability services, domestic violence interventions, expectant mother programs, health insurance providers, HIV/AIDS testing and screening sites, homeless shelters, medical care, local transportation, safer sex education, services for sexual assault, suicide prevention, transit to health care, tuberculosis screening sites, unemployment insurance, veterans assistance, childcare providers, and workers compensation assistance. Lack of transportation was cited as one of the barriers to accessing HIV services. Other noted challenges included respondents did not know where to go for services, cost or ineligibility, and waiting time to get an appointment to see a provider.

**Table 2.** Demographic Characteristics and HIV Routes of PLWHA Survey Respondents

| **Race/Ethnicity**[a] | N | % |
|---|---|---|
| Non-Hispanic white | 50 | 56.8% |
| Non-Hispanic black | 36 | 40.9% |
| Latino/Hispanic | 1 | 1.1% |
| Other race/ethnicity | 1 | 1.1% |
| **Total** | 88 | 99.9%* |
| **Sex** | | |
| Male | 64 | 72.7% |
| Female | 22 | 25.0% |
| Transgender | 2 | 2.2% |
| **Total** | 88 | 99.9%* |
| **HIV Transmission Route** | | |
| MSM[b] | 55 | 61.8% |
| Heterosexual | 8 | 9.0% |
| IDU[c] | 7 | 7.9% |
| MSM/IDU | 2 | 2.2% |
| Pediatric[†] | 0 | 0.0% |
| Other risk[‡] | 17 | 19.1% |
| **Total** | 89 | 100% |

**Notes:** [a]Survey respondents were asked to self-report their race and, separate from race, their ethnicity. [b]Men having sex with men. [c]Intravenous drug use.

[†]Includes those under 15 years of age with a reported HIV transmission route of perinatal mother-to-child and those with no reported transmission route. [‡]Other risk includes occupational exposure, recipient of transfusion with blood products, and no risk reported. Respondents could report more than one transmission category.

### *PLWHA Survey*

Eighty-nine (n=89) HIV positive participants voluntarily completed and returned the PLWHA Survey. The characteristics and HIV transmission route of the survey respondents are listed in Table 2. Respondents were predominantly male (n=64, 72.7%), English-speaking (96.6%) and born in the U.S. (94.4%). The ages of respondents ranged from 20 to 74 years, with a median age of 46. Whites

represented the majority of individuals completing the survey (n=50, 56.8%), followed by blacks (n=36, 40.9%), and Hispanics (1.1%). Of the 42 participants who responded to the question involving sexual orientation, 17 (42.5%) said they were heterosexual/straight, 2 (5.6%) said they were bisexual, and 1 claimed to be transgender. (From answers to other questions, we can assume that those not answering the sexual orientation question, 46 in all, or 51.7%, were likely homosexual or bisexual.) Asked how they thought they became infected, most (n=55, 61.8%) said men having sex with men (MSM), next was heterosexual contact (n=8, 9.0%), followed by intravenous drug use (n=7, 7.9%). Two (2.2%) said MSM or IDU (intravenous drug use). Over 10 percent (10.1%) reported "unknown" or "other" route. Among survey respondents, most (89.0%) were diagnosed with HIV disease for more than two years, and 39% reported they had been diagnosed with AIDS, which remained the same from the previous needs assessment findings.

Other findings, from the PLWHA survey, were that only 14 (15.7%) reported using illegal drugs in the past year; 13 (14.6%) reported as being homeless in the past year; nine percent (9.0%) reported as having been in jail or prison in the past year. While 82.1% of respondents completed vocational, some high school or at least some college education, 15.7% did not finish high school.

Some survey respondents (39.3%) reported first accessing HIV non-medical services within one month of initial HIV diagnosis, while 24.8% first accessed those services between three and 12 months after diagnosis, and 13.5% delayed more than one year to access non-medical services. Table 3 shows the numerical ranking and list of non-medical HIV services not currently offered through Ryan White Part B funding identified by the respondents. Non-medical case management (21%), transportation to care or service appointments (16%), and dental services such as check-ups, fillings, and extractions (16%) represent the top three non-medical services.

Table 4 illustrates the numerical ranking and list of services identified by the respondents as gaps in care and services that need to be addressed. Eye care (23%), rent assistance (22%), and utility assistance (22%) represent the top three gaps in care and services as identified by the respondents.

*Service Provider Survey*

The provider survey was sent to more than 60 providers. Only nine providers participated in the survey, which is a very low response rate. Six respondents were administrators, and three respondents were case managers from various agencies within the 26-county area. While the response rate was small, there was relevant information discovered from the nine respondents. Proper training, booklets, and informational materials were requested by the survey respondents to improve the quality of services for PLWHA within the 26-county area.

**Table 3.** Non-Medical HIV Services Not Currently Offered Through Ryan White Part B Funding

| Rank | Non-Medical HIV Services | Frequency | % |
|---|---|---|---|
| 1 | Non-medical case management | 32 | 20.91 |
| 2 | Transportation to care or service appointments | 24 | 15.69 |
| 3 | Dental (checkups, fillings, extractions) | 24 | 15.69 |
| 4 | Translation services | 23 | 15.03 |
| 5 | Food bank | 21 | 13.73 |
| 6 | Psychosocial support | 17 | 11.11 |
| 7 | Immune assistance plan | 12 | 7.84 |
| | Total | 153 | 100.0 |

**Table 4.** Identified Gaps in Care and Services

| Rank | Services | Frequency | % |
|---|---|---|---|
| 1 | Eye care | 39 | 22.8 |
| 2 | Rent Assistance | 38 | 22.2 |
| 3 | Utility Assistance | 38 | 22.2 |
| 4 | Housing Assistance | 22 | 12.9 |
| 5 | Support groups | 17 | 9.9 |
| 6 | No responses | 17 | 9.9 |
| | Total | 171 | 99.9 |

*Focus Groups*

A total of 54 people volunteered to participate in the focus group sessions. Forty males and 14 females participated in the focus groups. The average age of the participants was 50 years. The lowest age was 27 years, and the oldest person was 59 years. A total of 36 Caucasians/white not Hispanic, 16 African Americans/black, and two American

Indians participated in the focus group sessions. Of the focus group participants, 32 (59%) self-identified as "homosexual" (i.e., MSM), 16 (30%) self-identified as "heterosexual" (i.e., straight), four (7%) self-identified as "bi-sexual," and two (4%) self-identified as "other" (i.e., non-specified).

Common themes were found from the focus group data. The themes were service availability, utilization, access, satisfaction with services, quality and barriers to services, and unmet needs. The main items listed under the service availability theme were dental and medical services that are located in the metropolitan area in Middle Tennessee and local health departments. The feedback responses for the theme "utilization" included support groups, mental health services, dental services, and utilization of available transportation as the most critical HIV-related services that PLWHA are using now or have used in the last year. Under the access theme, respondents self-reported experiencing financial difficulties (e.g., no insurance, signing up for insurance/waiting period, no income, relocation costs, cost of living changes, and lack of local resources) as the reasons care was not accessed for 12 or more months. Most respondents indicated that they were satisfied with the pharmacies and various private primary care physicians within the local areas along with two agencies (Nashville Cares and the Vanderbilt Comprehensive Care Center) located in a metropolitan area within Middle Tennessee. Under the satisfaction with the quality of services theme, respondents identified transportation services, re-certification steps to obtain insurance, and access to primary care as the things that clients would like to see changed. Discriminatory practices and being discriminated against were listed as barriers to accessing services. The last identified theme was unmet needs. Participants listed the following: 1) lack of local access to primary care services, 2) lack of transportation, 3) nutritional needs not being met, 4) unsure of resources, 5) only having a nurse practitioner providing primary care services instead of a doctor, and 6) the long waiting time to see nurses and doctors.

**Study Limitations**

The use of a convenience sample limits the application of the results to be generalizable. Another limitation of the study was low response rates on the surveys and a short length of time to promote the study to the target population, which affected the sample size. Also, the PLWHA Survey was only distributed primarily through the main community agencies within the 26-county area. As a consequence, individuals who were not clients of these agencies, as well as those not currently engaged in HIV-related services, might not have been aware of the opportunity to participate in the study. In general, the potential pool of participants was limited to individuals currently receiving HIV-related services, and the results could not be generalized to all PLWHA other than those who completed the survey and volunteered for the focus groups.

**Discussion**

The CBPR approach was used to guide the process of conducting the needs assessment project among faculty researchers and community partners. As a result of this collaboration, an epidemiological data assessment, resource audit, surveys, and focus groups were conducted to complete the needs assessment project. The epidemiological assessment identified the population living with HIV in Tennessee (i.e., 26-county rural area). Although the total number of prevalent cases of HIV disease is small in the 26-county area, these cases were distributed over a large and diverse geographic area with generally fewer medical and support services available for HIV-infected persons, which poses an additional challenge for people living with HIV in the 26-county area. The resource audit revealed that PLWHA identified 18 non-medical support service needs within the geographic area. The surveys and focus groups also provided varying perspectives to existing gaps in care services.

**Conclusions**

The purposes of this study were to describe collaboration of faculty researchers from Tennessee State University and community partners, to conduct a needs assessment project of people living with HIV/AIDS related to their HIV-AIDS continuum of care and services in the 26-county rural area, and present the results of this project. The collaborative partnership approach helped to identify the non-medical service needs and interpret the results of the study. The results indicated that there were few HIV positive individuals linked to HIV non-medical services within one month of being diagnosed with the HIV disease. Additionally, numerous survey respondents noted that early intervention services, routine dental services, non-medical case management, eye care, psychosocial support, emergency food bank, rent assistance, utility

assistance, and adequate transportation to appointments are critical non-medical services for meeting the needs of PLWHA. This study identified the needs of PLWHA who participated in the project and were currently receiving services through community agencies in the 26-county rural area.

This study may not represent the overall needs of PLWHA who are residing in the 26-county rural area and who are not currently receiving services. This needs assessment was the first step toward identifying the non-medical service needs of PLWHA in the 26-county rural area. The results of this study will be used by Community HIV/AIDS Partnership members as it relates to making recommendations to the Tennessee Department of Health for direct planning and resource allocation of Ryan White HIV/AIDS (Part B) funds. The findings and recommendations from this needs assessment study can also support community leaders and health care providers in planning and allocating resources for non-medical services of PLWHA in rural communities.

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